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ABSTRACT

The author visited selected countries in Europe to examine the process of disabled minority group evolution and to identify practical knowledge useful in stimulating smilar development in the United States. Previous research revealed that many countries in Europe appeared to be far ahead of the United States in the development of organizations of the disabled. Forty-four leaders of handicapped organizations in the United Kingdom and Sweden were identified and interviewed. Interview notes were made during discussions and, while each interview was open ended, care was taken to cover several points, including history of the organization, the individual's role in it, goals, problems, tactics utilized, assessment of success, factors contributing to success, degree of formal and informal representation in government agencies and societal institutions that impact the lives of disabled persons, leadership and its development, philosophy of disablement, and advice for the United States. Among the 17 conclusions reached were the following: (1) organizations involving disabled persons tend to evolve, beginning with control by able-bodied individuals in voluntary groups for the disabled and concluding in groups of the disabled under their own control; (2) early aspirations of disabled groups tend to focus on urgent practical problems such as mobility, access, housing, income, and employment but later move into cultural and societal participative goals; (3) the degree of success in evolution of disabled groups depends upon availability of resources to supply group maintenance needs and employ salaried staff; and (4) several problems typically manifest themselves including the need for strong, realistic leadership; overcoming apathy; avoiding personality conflicts and explorations; avoiding self defeating, short term goals; and using power gained in a mature, responsible nature. Appended is information on members of the Central Committee of National Associations of the Handicapped. (SW)

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UCIR is located at Michigan State University and is funded by the National Institute of Handicapped Research, U.S. Department of Education, Washington, D.C. The center welcomes comments and inquiries.

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The points of view expressed in this publication are those of the author and do not necessarily represent the opinions or policy of the National Institute of Handicapped Research, the World Rehabilitation Fund, or the University Center for International Rehabilitation.

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SOCIAL JUSTICE THROUGH HANDICAPPED POWER: PERSPECTIVES FROM ENGLAND AND SWEDEN

G. D. Carnes

April 1982

INTRODUCTION

The Disabled as a Minority Group

The classic book by Beatrice Wright *Physical Disability: A Psychological Approach* (1960) articulates the plight of the handicapped and places their situation in theoretical perspective. This widely accepted view states that, as a minority group, the disabled are subject to the same process of stereotyping, prejudicial attitudes, and discriminatory behavior as any other minority group. The process is the same; only the content of the devaluating attitudes differs. She documents through anecdotes and research the ways in which handicapped individuals are denied opportunities for full participation in society, and she cites barriers ranging from attitudes to environmental restrictions.

Wright argues that disabled persons are viewed as helpless, dependent, and sad, and the legitimate limitations of a disabled condition are spread irrationally into other life functions in which they are quite capable. The consequences are discriminatory restriction in employment potential, historical segregation in education, and general opposition to a broad integration of the disabled into society. Numerous writers have documented the fact that those who are more prejudiced towards racial minority groups are also most prone to discriminate against the disabled. The lowered income levels and educational attainments, the lessened life achievements in comparison to ability, and the impact on voting, marriage, and continuing success are all classic impairments to life functioning found among minority groups and they are equally true of the handicapped.

Analyses of these problems have demonstrated that the causes are not inherent in the minority populations but are direct consequences of the complex disruptive forces associated with prejudice and discrimination. Such disruption includes the psychological demoralization and lessened self-expectation that are derived from negative attitudes, as well as the indirect or blatant denial of opportunity derived from environmental barriers. Such factors tend to become additive, reinforcing each other, and prevent resolution of the separate parts. As will become clear in later sections of this paper, this vicious circle of discrimination is not the only similarity between minority groups and groups of the disabled.

Berry and Tischler (1978) write the following with reference to racial minority problems, but its application to handicapped individuals should be kept in mind:

> The members of dominant groups like to feel that subordinate peoples regard them with admiration, respect, and even gratitude for the favors they have received. Colonial powers insist that their subjects, except for disgruntled agitators, deeply appreciate the blessings that have been brought to them by their conquerors -peace and order, relief from tyrants, sanitation and medical care, commerce and industry, education, Christianity, and a higher standard of living. Dominant people everywhere, it seems, comfort themselves with stereotypes of contented, unambitious, humble subordinates, blissfully ignorant of the cares and burdens of superiority. (p. 375)

The Struggle for Equality

Sociologists postulate that a minority group has three main avenues of reaction when faced with the oppressive condition: acceptance, withdrawal, or aggression (Berry and Tischler, 1978). These options may be either on the psychological or physical level, but often the two levels parallel each other. Historians indicate that mankind has evolved considerably since the Middle Ages when serfs were treated as, and considered themselves to be, fixed to the land as much as trees or buildings. This enlightenment in notions of freedom is repeated over and over again through history with respect to nations, peoples, and minority groups. Some social psychologists postulate that a change in the psychological level of reaction to oppression precedes and is required for those actions producing change at the physical level. History clearly shows that majorities seldom easily relinquish the exploitative advantage offered by an oppressive structure. It is the thesis of this present report that certain broad patterns of process are ascertainable in the evolution towards equality in racial minority groups and that these will manifest themselves with the disabled.

It is this writer's view that the initial reaction to oppression is acceptance. This is manifested by apathy, resignation, and often an introjection of the prejudicial attitude that results in a self-perception of inferiority. Roughly speaking, the next step is withdrawal as manifested, for example, in a "separate but equal" concept. The third step towards equality is that of aggression,

characterized in some instances by violent struggle, and by other lesser forms of aggression such as social disobedience, picketing, strikes, and militant persuasive attempts. The author also suggests that there is a complex interaction between the prevailing view within a society with regard to the rights of man and the degree of success one may achieve in striving for freedom. There are a number of other factors that influence the process including economic conditions, political directions, leadership development, and effective utilization of tactics and resources.

It would be vastly out of the scope of this paper to detail an application of this rough schema to world history, but the reader is invited to consider the decline of the colonial powers, the black civil rights movement, and even the process of raising children as cases in point. Finally, one must keep in mind the truism that independence without the development of mature responsibility leads to disaster.

Prejudicial attitudes toward the handicapped have often been cloaked in the compassionate-appearing protest that "they need to be taken care of," much as the Southern slave owner protested that his property was incapable of independence and needed to be taken care of. In our degree of enlightenment today it is easy to forget that not too many years ago the disabled were devoid of any human rights, viewed as freaks and misfits with defects interpreted as punishment for sin, and frequently infused with the notion that "evil comes from evil looks." When the notion emerged that education was appropriate for disabled persons, the first applications were in strictly segregated facilities. Only recently has mainstreaming become accepted, let alone the law of the land.

Debate continues within the disabled community as to the degree and type of integration that is desirable, and the tactics to be utilized are hotly contested. Certainly within the United States (US), great strides have been made in the last few decades toward increased opportunity for the disabled, culminating in the landmark Vocational Rehabilitation Act of 1973. Almost for the first time, the handicapped were legally recognized as a minority group that needed protection from discrimination. It is not surprising that this legislation paralleled emergence of the first national efforts by handicapped organizations in conjunction with pressures from the longer established and more powerful voluntary and professional organizations for the handicapped.

Earlier, certain needs of disabled persons had been addressed by many state legislatures, but often these were oriented around a charity approach rather than towards equality of opportunity. Organizations for minority groups, led by liberal members of the majority community, typically precede emergence of organizations of the minority, and this continues to be the case with respect to the handicapped in the US. However, the historical pattern is for minorities to seek and obtain organizations exclusively of themselves to confront and negotiate with society. As will be discussed later, some contend that groups for minorities can, by their nature, only achieve objectives short of true equality. Today, the US is at the point of transition from groups for the handicapped to those of the handicapped with the emergence of a national handicapped movement.

An Opportunity, Not Special Privilege

Historically, the rugged individualism, free-will philosophy of American society has made it difficult for citizens to understand, let alone accept, the role that economic and other forms of determinism play in people's lives. Only recently has there been much discussion about the complex network of forces that mold self-concepts, limit opportunities, and determine the fates of common man. It is a notion that frightens many and is resisted by most. Yet with minority groups, these constraining forces are even more crushing, because additional barriers are added to those commonly experienced.

It is difficult but far easier to convey the consequences of psychological devaluation than it is to convey the effects of the loss of common social technologies that are taken for granted. What good is a job if there are no transportation systems usable by a severely disabled person to reach it? Of what value is the right to vote if the polling booth is up several flights of stairs and there is no elevator for the wheelchair user? Of what value are libraries, public colleges, and cultural events if the visually disabled citizen cannot use them? That handicapped citizens pay taxes for their support, that access to these resources is essential for true equality of opportunity in our competitive society, and that there is an inalienable right to their access is a notion not yet prevalent in our society.

Too often the point is misinterpreted as pleading for expensive special

privileges. Given this misconstruction, when resources are scarce, as in times of financial austerity, it becomes vastly more difficult to obtain the modification of technologies or systems that are needed in order for the handicapped to have true equality of opportunity. A charity orientation toward the disabled further lends itself to this misconstruction. Therefore, acceptance of the handicapped individual as independent, responsible, and self-supporting is essential if the need for, or right to, social systems and institutions is credible. Changing the view of a society toward a minority group is a requirement of its leaders that must parallel, if not precede, attempts toward tangible reductions in discrimination and availability of opportunity.

BACKGROUND OF STUDY

Previous Research

During a previous investigation in Europe, the writer felt that many countries appeared to be far ahead of the United States in the development of organizations of the disabled (Carnes, 1979). Although all appeared ahead of the US, there were apparent differences in these developments, and the degree of evolution of disabled groups appeared positively correlated with an emergence of progressive social policies and benefits for the disabled. Several countries appeared to have an excellent evolution of organizations of the handicapped with very significant representation in government at all levels. Other research published in the past few years has discussed concepts such as the normalization principle of the Scandinavian nations, which requires society to make significant adaptation for the disabled and does not require that accommodation be made exclusively by the disabled person. These influences strongly suggested that a study in-depth of the handicapped movement in Europe might assist development in the US.

United States Contrasts

The writer's background as a rehabilitation client, rehabilitation professional, rehabilitation educator, and currently as a rehabilitation/mental health administrator led to the belief that the United States had lessons to learn from Europe in matters of handicapped organization and influence. While differences appeared largely those of degree, not of kind, they added up to the impression that Europe was far better in almost every comparison.

The United States has very few truly national organizations composed of and limited to disabled individuals. Rather, disabled persons are largely represented by organizations for the disabled. Sometimes these groups include handicapped individuals amid a majority of nondisabled persons who have an interest in the particular kind of handicapping condition, and sometimes they are largely composed of professionals working in some disablility area. These organizations, therefore, cannot be assumed to speak for the disabled and their capacity for resort to social actions, e.g. demonstrations, boycotts, and the like, largely does not exist.

Nondisabled groups representing the handicapped are notoriously unwilling to engage in the tactics that appeared more common in Europe. A great point is made in Europe that handicapped persons must form their own groups, democratically elect their representatives, and internally resolve their priorities, policies, and strategies to influence society.

Historically, the United States has not financially supported handicapped organizations, except indirectly, and that support has gone primarily to nondisabled voluntary groups. In contrast, previous research led to the impression that Europe heavily supported handicapped organizations, often directly. The writer has personally experienced and witnessed many times the futile struggle of handicapped groups to survive without resources. All energy is expended in keeping the group alive; there is little left to confront society. A clear contrast is the absence of paid staff among groups of the disabled in the United States. Paid staff appeared to afford European counterparts the capacity to carry out campaigns and other measures.

Some implicit US change has been seen in the last few years in the award of federal grants to establish independent living centers. The grants are awarded to organizations largely composed of handicapped persons.

In the United States, there is an absence of regulations or policy establishing procedures that ensure that democratically elected disabled persons from handicapped organizations are involved in legislation, budgets, regulations, or procedures directly affecting the handicapped. Although the 1973 Vocational Rehabilitation Act requires that state agencies develop consumer involvement programs, a 1978 study revealed that a vast majority of these agencies had ignored this requirement, and the involvement strategies developed by the rest

were mail surveys or equally superficial procedures. Again, while representation by handicapped persons is encouraged or even required on some specified boards, panels, or advisory groups, the named individuals are typically selected, as contrasted with election by the disabled. Thus, individuals can be named, and often are, because of their lack of unacceptable attitudes, nonaggressiveness, and/or favorableness to the nondisabled power structure.

In contrast, European literature emphasizes the true representativeness of spokespersons from the handicapped community. It is difficult, if not impossible, to generate democratically elected handicapped representatives without the requisite broad-based support structure of disabled groups. This fact is often used to explain away charges of "Uncle Tom" appointments to handicapped advisory committees. Europe appeared far better than the US in the representativeness of persons involved in the required or traditional dialogue between the handicapped community and government at all levels.

Many types of disabilities not usually organized in the United States appeared organized in Europe. These appeared to be focused on certain organ system pathologies or minor disease areas, e.g. diabetes, heart conditions, skin disease, and such, which are not viewed as disabilities here. While in some sense, such problems are "minor" compared to paraplegia and blindness, for instance, potential membership is enormous and societal influence formidable, if directed. Problems in specific life function areas have also led to European handicapped organizations such as automobile drivers clubs, sexual information services, and so forth. The impression gained was that such focused activities had been very successful in addressing life function problems that cut across many categories of disability.

Probably most important of all, until the emergence of the American Coalition of Citizens with Disabilities (ACCD), there was a total absence of any national-level coordination in the handicapped community. The membership of this organization demonstrates the contrast between the US and European view of handicapped organizations. Any group or individual may become a member of ACCD. Voting privileges are restricted to groups having memberships in which at least 50% are handicapped, and there must be written assurances that the group is controlled by the handicapped. Membership on the Board of Directors of ACCD is restricted to handicapped persons. However, a large portion of the

total membership of the organization are (albeit nonvoting) nonhandicapped run organizations. In Europe, handicapped organizations were comprised totally of handicapped individuals.

In addition to lack of coordination at the national level, lack of coordination appears equally evident in most local and state level spheres of activity. Consequently, the disabled community, to the extent it is organized, speaks with contradictory, fragmented, and ineffectual voices to society and its institutions. Legislators complain of multiple demands upon their time, and competing, often unrealistic desires from differing handicapped groups.

Following the 1977 White House Conference on the Handicapped, and stimulated by the International Year of Disabled Persons, some small progress in coordination among handicapped groups and individuals appears to have materialized. However, this seems very limited in scope and ineffectual in action compared to Europe's complex structure and highly developed coordination systems. Obviously, it is far better for the handicapped community to be working together, joining forces, establishing priorities, agreeing on strategies, and mutually reviewing successes and failures. This would appear the best way to enhance handicapped influence, and, in contrast to the United States, Europe seemed superior in this also.

Purpose of Study

From these influences and observations, the author proposed to visit selected countries in Europe and investigate the degree of evolution of handicapped groups. If, as anticipated, their development was ahead of the US, those factors that appeared responsible were to be identified and reviewed for potential transfer. Specific factors underlying relative success or failure were to be scrutinized and considered for US applications. Investigation would also treat the history of selected handicapped groups, problems experienced, solutions found or remaining difficulties, leadership, and objective indications of influence upon society. Thus, the overall purpose was two-fold: 1) a theoretical examination of the process of disabled minority group evolution and 2) identification of practical knowledge useful in stimulating similar development in the United States.

METHOD

Rationale

Time and financial limitations made it infeasible to study all possible countries. Therefore, two countries known from previous research to occupy differing points on the continuum of evolution were selected. Great Britain, while, in the author's opinion, ahead of the US, was considered less progressive by other countries and thus represented a lower point on the scale of development. Sweden was considered as occupying the most advanced point on this scale and stood in sharp contrast to Great Britain and the US.

Subjects

Leaders of handicapped organizations were identified and interviewed. A total of 31 individuals served as contacts in the United Kingdom (UK) and 14 in Sweden. To guard against distortion and excessive claims, counterpart governmental leaders and/or independent rehabilitation programs were contacted and also interviewed to verify the information collected. A total of six such individuals were contacted in the UK and eight in Sweden. Because of the importance of this safeguard upon the validity of information, the individuals were chosen with as much care as the disabled leaders.

Procedures

Identification of leaders began months before the visits and was facilitated by contacts made in the earlier research. On-site details were handled in Sweden by the Swedish Institute and in the UK by the Overseas Division of the Manpower Services Commission. A core of disabled leaders was initially identified in each country, but additions were made as information was collected and significant persons were named. Most of the investigation was conducted in the London, England and Stockholm, Sweden areas, but several trips were made to other localities, and many individuals came to these cities for interviews.

Interview notes were made during discussions and, while each interview was open-ended, care was taken to always cover several points. These included: history of the organization, the individual's role in it, goals, problems, tactics utilized, assessment of success, factors contributing to success, degree of formal and informal representation in government agencies and societal institutions that

impact the lives of disabled persons, leadership and its development, philosophy of disablement, and advice for the US. The same questions were submitted to the counterpart government officials. Where contradictions were implied, these discrepancies were posed to relevant informants for clarification or dispute. In all instances, strict confidentiality regarding identification of the informant was guaranteed. This is an extremely important point and resulted in the volunteering of facts not otherwise obtainable.

Finally, identification of local publications was sought and copies obtained of relevant literature whenever possible. This resulted in about 50 pounds of reading matter which remains under study at the time of this writing.

RESULTS: GREAT BRITAIN

For purposes of discussion, organizations in the United Kingdom can roughly be divided into voluntary associations and groups of the disabled. However, these blend into each other and some organizations exhibit special attributes that merit additional discussion. As predicted, voluntary associations clearly prevailed in the UK among the great diversity of organizations concerned with disablement. A superficial examination left one impressed with the broad array of groups focusing upon all aspects of the lives of the handicapped. In the author's opinion, this range demonstrated how limited the focus has been in the US until now.

In reviewing the history of such organizational richness, the author noted a clear trend for those types of foci now apparent in the United States to have developed much earlier in the UK. Many informants suggested that the heavy civilian casualties during WWII may have been responsible in part for the initial degree of social acceptance of several types of programs and for the assumption of government responsibility. Certainly, WWII did produce a much higher percentage of disabled persons in society for a longer period of time than has been the case in the US in recent history.

Voluntary Associations

Many reasons suggest that a discussion of voluntary associations begin with the **Royal Association for Disability and Rehabilitation (RADAR).** The two

largest voluntary associations combined in 1976 to form RADAR, which acts to stimulate coordination of other disablement groups, provide technical information, foster and fund research, finance diverse projects, and consult with the government on relevant topics. RADAR operates from donations and government grants.

The interweaving of RADAR throughout disablement in the UK is so complex that RADAR is best viewed not as the spearhead for organized disablement work but, rather, a fabric within which almost all else is woven. While RADAR provides or stimulates service provision in areas of need, its main importance to this writing is its role in organizational development and coordination.

Evaluations of RADAR were generally positive, but many leaders of the disabled referred to it as "disappointing" and charged that it "did not really speak for the disabled." It seemed evident that many of these negative assessments stemmed from the view that RADAR was not sufficiently aggressive in action or viewpoint in matters of disability. While disabled individuals are on RADAR's staff and advisory committees, and while organizations of the disabled have voice in its complex system of committees and boards, it is not evident that the disabled themselves control policies.

One knowledgeable informant alleged that a number of heads of voluntary organizations have knighthood ambitions. Meritorious service in the field of disablement is one path to honors from the Queen, and such aspirations on the part of some voluntary association leaders are disruptive to objective efforts in the field of disablement.

Three organizations, the Spastic Society, the National Society for Mentally Handicapped Children and Adults (NSMHCA) and the National Association for Mental Health (MIND) are typical voluntary groups that have a characteristic in common. Informants in these associations discussed how the disabling conditions of their clients impaired their capacity for true representation.

The **Spastic Society** began as a parents' group for people with cerebral palsied children, and so it largely remains today, although it is heavily influenced in operations and policy by its professional staff. The Spastic Society has many facilities, provides numerous services, finances demonstrations and research projects, and cooperates heavily with other related organizations. One infor-

mant discussed objectively and in detail the problems of power balance between professional staff and parents of their clients, both children and adult. Understandably, concerned parents sometimes are overprotective and, through advisory groups, will tend to produce overprotective agencies. There appeared to be limited consumer representation, and the emphasis was on the unrealism of their clients playing a very significant role because of their multiple handicapping conditions, especially cognitive loss.

The **National Society for Mentally Handicapped Children and Adults (NSMHCA)** stressed similar problems. This organization concerns itself with mentally subnormal individuals and provides a great variety and number of services in addition to demonstration projects and reseach. It also operates several facilities. Like several other voluntary groups, the informant emphasized that they operated largely by contributions and accepted government funds only for specific projects. The implication was that this ieft a freer hand in policy. Like most voluntary associations, there is a national system uniting the 500 local chapters, and parents are the dominant influence. As with the Spastic Society, the limited extent of consumer representation by virtue of the disability was emphasized, although higher levels of the mentally retarded appeared to have some involvement. Like the other two organizations in this grouping, while not a true "pressure group," one of their roles is to consult with and influence government regarding the needs of their client category.

While all three groups spoke of needs for integration, NSMHCA and MIND especially emphasized this problem. NSMHCA operates a system of "Gateway Clubs" to stimulate the integration of mentally retarded persons into society. The NSMHCA informant also expressed concerns about the mentally retarded being left out by other disability groups in joint actions and their organizations somehow not viewed as true handicapped groups.

There appeared to be some conflicts between NSMHCA and the National Association for Mental Health (MIND). Some individuals believe that MIND exclusively focuses on mental illness but projects, unwarrantedly, a broader scope in public relations regarding its activities.

The **National Association for Mental Health** informant stated that the term MIND really did not stand for anything but had become widely used for identification purposes by their organization. The nature of MIND may be gained

from the following quotation taken from their *Annual Review 1978-1979* (1980):

> MIND (National Association for Mental Health) is a registered charity operating in England and Wales. It exists to promote better mental health and opportunities for personal development. It also seeks to improve voluntary and statutory mental health services and to develop the concerns and common interests of patients, families, those who provide services, and the public. As a membership organization it invites the cooperation of individuals, organizations, local mental health associations and other groups who support its basic aims.
>
> 1. To improve knowledge of mental health and the causes and consequences of mental illness and handicap.
> 2. To encourage and demonstrate good practice in the prevention and treatment of mental disorder and to improve access to better care, rehabilitation, education and welfare for the mentally ill and handicapped.
> 3. To raise the standards of existing services and to encourage new and improved forms of care and treatment.
> 4. To uphold the rights and meet the needs of patients, ex-patients, their relatives and mental health workers; to combat the stigma, fear and prejudice still associated with mental illness.
> 5. To mobilize opinion in support of mental health activities through volunteers, self-help and community groups, professional workers and the public.
> 6. To raise funds for the activities of MIND, its local associations and other concerned groups.
> 7. To sponsor research, collect and distribute information and issue publications.
> 8. To provide advisory, counseling and advocacy services.

9. While fulfilling its existing obligations in the field of residential care, to encourage the provision of appropriate and preferably pioneering services in the community.
10. To maintain a programme of education and training for professional mental health workers, administrators, volunteers and members of the lay public, and educationalists. (p. 1)

The MIND informant admitted that consumer representation was lacking and needed more development although there were obvious difficulties. The poor state facilities and treatment for mental illness in the UK were stressed along with the efforts of MIND to improve matters. Local chapters were viewed as more or less successful in their influence upon local governments, but representation of the mentally ill within treatment institutions was seen as almost absent. The 180 local chapters are a mixture of ex-patients and professionals in membership, but a number of self-help groups act as an informal source of representation.

The informant felt that there was less public sympathy and support for the disability of mental illness, and that vocational rehabilitation programs were very inadequate. Since 25% of MIND's funds are received from the government, it was stated that tactics did not include more aggressive strategies such as demonstrations. They did represent clients in court and influenced public policy through legal test cases. The feeling was expressed that current views and treatment of mental illness worked against concepts of self-determination and consumer representation in this field.

The Royal National Institute for the Deaf and the Royal National Institute for the Blind pose some interesting similarities and differences. Both are large national organizations with local chapters, concern themselves with a single sensory disability, provide a variety of programs and services, operate various facilities concerned with their disability focus, have a complex representation system that involves consumers, and cooperate with a variety of other organizations.

The informant from the **Royal National Institute for the Deaf (RNID)** stressed the limited extent to which government funds were accepted and then

only for specific projects. However, RNID was not characterized as a radical group as, in contrast, was the National Union of the Deaf. The need for specialized services and professionals was emphasized, and it was suggested that this was in the face of opposite national forces. Integration was an important goal and a national system of clubs was organized in part toward assisting this goal. Professionalism was a main theme, as the organization has 50 staff members in the national office and over 500 in the national system. Pressure group activity was accomplished through an organization formed with three other associations. This combined group achieved regular meetings with the Minister for the Disabled.

In contrast, the **Royal National Institute for the Blind (RNIB)** acts as a quasi agent for the government in many services and programs. Heavy government funding finances specific vocational training programs and publication of Braille and Talking Book materials. RNIB represents the blind in diverse national committees and acts to advise government in many ways. It would require pages even to summarize the broad extent and diversity of programs that range from maintaining holiday hotels to providing vocational placement for higher level occupations such as professional and commercial positions.

The RNIB executive council consists of 120 members, divided among several categories. One category of representation is limited to elected representatives from organizations of the blind. This consumer category constitutes 30% of the membership on the RNIB executive council. One critic detailed the struggle to obtain an increase in this percentage, including scheduling a demonstration just before the meeting of the council. RNIB counters that though the consumer category may be limited to 30%, there are many blind representatives in other representation categories of the council. But the blind consumers argue that there is a philosophic difference between the blind representatives who are elected by their groups and the blind individuals who are appointed by RNIB.

Despite considerable disagreement with its policies, informants from groups of the blind admit that RNIB plays a dominant role in blind disablement. RNIB informants stress program and service growth in the past few years and the general improvement in the lives of the blind in the UK. Critics imply that the RNIB exhibits overly cautious viewpoints because of close government ties and

that it lacks innovativeness, especially in the job development area. It was acknowledged that until recently the blind were the best served, but gains by other types of disability had severely cut the relative advantages of the blind.

RNIB appeared to be for the blind what RADAR was for general disablement. In contrast to local groups of the blind, where problems might be slugged out and solved on a case-by-case basis with a focus on tangible service offerings, the focus of RNIB, like RADAR, appeared to be on the general problems of the group, such as: developing and furnishing equipment, researching and developing needed capacities, promoting specialized training, coordinating activities of many associations concerned with blindness, and attempting to mobilize a group consensus.

The **Disability Alliance**, headed by Peter Townsend, defied classification with any other group. The group's emphasis is on high-level conceptualization and political influence on behalf of all disabilities. The organization is made up of many cooperating groups, and its philosophy emphasizes a sociological approach wherein the disabled are placed in the context of problems faced by all minority and disadvantaged social class groupings. Critics charge that the alliance is too political and too aligned with the Labor Party. Almost everyone agreed that it was radical in viewpoint yet appeared not to engage in agressive tactics.

Attempts have been made to combine the Disability Alliance with the Disablement Income Group (to be discussed later), but such efforts have been resisted by factions of each group. The Disability Alliance appeared to be less composed of disabled persons than of well-educated, compassionate, and dedicated nondisabled workers in their cause. It was clear that some disabled leaders resent being classified with "poor people," as they charge the Disability Alliance of doing, and they felt the approach was too akin to the Labor Party's philosophy of socialism.

Designated Governmental Advisory Groups

Some groups were identified that are, strictly speaking, neither voluntary nor organizations of the disabled. The **Committee Upon Restrictions Against the Handicapped** and the **All Party Group Upon Disablement** do draw membership in considerable part from disabled leaders. They have established and formal

advisory functions to the government. Staff functions are paid by government financing, e.g. from the Department of Health and Social Services or sometimes through third parties such as RADAR. The Committee Upon Restrictions Against the Handicapped seeks to ascertain the degree and specific cases of discrimination against the handicapped, while the All Party Group Upon Disablement represents a formal avenue of dialogue between government and handicapped leaders. One gains the impression that, while these committees function, their significance is far less than other pressures exercised; but many disabled leaders had "worked up" through these routes. Minutes were kept of meetings, reports and recommendations were submitted to government, and some administrative policies had been affected. There was a lack of clarity regarding many aspects of these groups, primarily because informants did not consider them important enough to provide much detail.

Also considered by disabled informants to be of minor importance were the national system of **disablement advisory committees** and the **National Advisory Council on Employment of Disabled People.** These constitute a very formal and legally mandated activity. At the time of research, the system was under review but continued to have membership composed of representatives from labor, management, and government within which some disabled were appointed. Disabled individuals were more likely to appear on various boards and panels when topics of disablement were the focus.

A local disablement advisory committee (DAC) has several legally mandated responsibilities--one is in the area of contested adjudications involving the work quota scheme for the handicapped, registration, jobs limited to handicapped incumbents, and so forth. Both the national and local groups serve advisory roles, but their alleged lack of influence produces continued deterioration of interest and involvement within the handicapped community. This was recognized by relevant government officials and is in part responsible for the current serious reconsideration of their function and structure. In fairness, it should be stated that a government official gave several examples where criticism funneled through this mechanism produced changes in specific service provision policy or practice.

There is in Parliament an identified **Minister for the Disabled** who relates to the previous groups very directly and to many other associations in a more or

less direct fashion. Every informant agreed this designation was a major achievement enabling the disabled to have what roughly corresponds in the US to their own cabinet-leveladvocate. The Minister for the Disabled acts for the disabled in Parliamentary matters and, through many structures, attempts to coordinate and advance legislative initiatives. Some informants question the caliber of the current incumbent but agreed that the office constituted a significant triumph for the disabled movement and facilitated legislative initiatives in a manner never before possible.

Special Purpose Organizations

There is another category of organization that is voluntary in nature yet focused on a very specific group or purpose. The **Forces Help Society and Lord Roberts Workshops** assists ex-enlisted military personnel when in need by a variety of services ranging from employment in their sheltered workshops, to cash grants and space in their retirement homes. Beyond established government benefits, this is one of a network of organizations for ex-military personnel, some of which are so specifically targeted as to focus only on persons from a particular military unit. Disablement is often found but not required in order to use these services. Unfortunately, the requirement that the workshops pay union scale wages is causing them to go out of business.

Physically Handicapped and Able Bodied is a national system of local groups designed to promote integration of the disabled through sports and recreation. One informant stated that the balance generally runs about 60% disabled to 40% able-bodied participants. Most local groups were considered to be moderately successful depending upon the criteria employed. The groups continue to exist, but their national impact upon attitudes toward the disabled is questionable. It was felt that they provided local sports capacity that was needed and did influence local attitudes. It was noteworthy that some handicapped leaders had earlier been administrators in these groups.

The **Disabled Living Foundation (DLF)** addresses a wide variety of problems encountered by all types of disability. Many handicapped leaders had at some time played roles relating to this organization, which, one informant volunteered, is the major project of Lady Hamilton. Finances are from contributions and government grants. The group's aims are described in the following:

> The Disabled Living Foundation is a charitable trust, the terms of reference of which include all disabilities (mental, physical, and sensory) together with multiple handicaps and the infirmities of age. The Foundation works on those aspects of ordinary life which present special problems and difficulties to disabled people of all ages and disabilities. (p. 24)

The foundation has four distinct services available for its consumers: an information service, incontinence advisory service, clothing advisory service, and aids center. The information service answers inquiries from disabled people, their families, and friends about subjects related to the lives of handicapped people, with the exception of purely medical matters. Studies into relevant aids and equipment for incontinent individuals have been conducted and information is provided to those affected by the problems and their families or concerned professionals. Problems of clothing for disabled people are addressed by another advisory service of the foundation, particularly helping the young and elderly.

The foundation also has a center that exhibits technical aids designed to reduce the effects of disability, including equipment that assists in activities of daily living for all age groups. Classes are offered for professionals who wish to become familiar with available technology and devices. Other studies into problems of disability include sports and recreation, music, gardening, employment, and housing adaptations, among others.

Informants stated that although it could not be considered a true pressure group, one additional objective of the DLF was to influence government on behalf of the disabled. Projects change from year to year depending upon perceived needs. Some disabled informants complained that need perception was too often influenced by those needs thought important by the well-intentioned charity worker rather than the disabled themselves. One informant charged that policy committee members were appointed from deep tradition within the prestige charity sector. This was denied by a DLF official who stated that disabled members were appointed to many panels and advisory groups.

The purpose of the organization called **Sexual Problems of the Disabled (SPOD)** is very specific. The organization is housed as part of the RADAR main

offices. It is partly supported by RADAR and by a government research grant, and it was fostered by many other associations, including the Spastic Society and one of the two parent RADAR associations. The SPOD informant stated there are 120 members, some from other organizations, from which a seven-member executive committee is elected. The functions of this association are described in the following quotation from their literature (SPOD, 1980).

> The Committee on Sexual and Personal Problems of the Disabled was set up in 1972 by the National Fund for Research into Crippling Diseases, with the object, at that time, of studying and advising on sexual problems as these might be experienced by disabled people in the United Kingdom.
>
> Accordingly, in mid-1975, SPOD (as the Committee came to be known) adopted a continuing function in the active field, with the aims of:
>
> a) stimulating public and professional awareness of sexual needs and difficulties among disabled people and of measures which may alleviate their problems in this respect.
> b) providing a centre for the collection and dissemination of information in this field, for disabled people themselves and for those concerned in their welfare.
> c) providing an advisory and referral service for disabled clients, therapists, counsellors and educators.
> d) arranging for training of those working among the disabled in the sexual aspects of disability. (p. 1)

Organizations of the Disabled

While many disabled leaders hotly contest whether the **Disablement Income Group (DIG)** is truly an organization of the disabled, its role in history and its broad-based support suggest that it merits first discussion. Its local branches are

made up both of workers for the disabled and disabled persons themselves, although the latter group is becoming more dominant according to some informants. Its original purpose was to secure an invalidity pension for the handicapped to offset the additional costs of life or forced nonproductivity. Many early achievements in legislative benefits for the disabled were attributed heavily to DIG by many informants, and numerous disabled leaders had been active in DIG.

The group designates an official lobbyist to Parliament. This lobbyist is himself severely disabled and has a long history of involvement in disabled organizations. DIG is financed by member dues, contributions, and specific grants from foundations. They are acknowledged as a prime pressure group and publish numerous tracts, brochures, and leaflets.

Currently, there is pressure to combine with the Disability Alliance, and this was debated during their summer 1980 annual general meeting in London. The rationale was to avoid duplication of effort and to profit mutually from the disabled power base of DIG and the political connections and academic respectability of the Disability Alliance. The motion was defeated following assertions that the Disability Alliance was too linked to a single party, that DIG might lose its consumer perspective, and that DIG should stick more closely to its initial objectives of income support. To the writer, the process of the meeting contained all the problems that many groups experience: parliamentary hair-splitting, confusing motions, petty debates, focus upon trivia, and vote swaying by impassioned pleas from leaders. Critics charged that DIG had "lost its way" and, thus, its force by pursuing multiple objectives. Others alleged that DIG really had become a group for the physically handicapped.

Representation to the national executive committee at the annual general meeting stemmed democratically from local associations, but controversy arose over a complex system of voting proxies that had been established in order to prevent policies being determined exclusively by those able to afford the trip to London. It was obvious that this well-intentioned administrative arrangement produced formidable procedural problems and bore a complex relationship to the policy power struggle. Many informants spoke of some leaders exploiting their positions for personal gain to the detriment of the handicapped; one stated that, "disablement is a growth industry" with too many high-salaried leaders.

The policies of DIG clearly had alienated some leaders of the sensory loss disability organizations, many of whom boycotted the association. One long-time member of DIG expressed sadly that it could not have survived in the early days without the support of powerful nondisabled persons, and as the disabled take over control, the organization is less efficient and effective. Comparison was made to the labor movement in which, allegedly, democratically derived union representatives are inferior in quality and hence in effectiveness to their management adversaries. However, government officials spoke very respectfully of DIG and almost everyone acknowledged its significant influence.

Some organizations appear to have influence beyond their size, and this certainly was the case for the **Association of Disabled Professionals.** One informant stated that a very substantial degree of disabled leadership had risen from this small association of about 500 members. The explanation was that these individual's high intelligence, aggressiveness, better position in life, and broader contacts with powerful people naturally led to disproportionate emergence of leadership. The association's secretary is funded by RADAR, and the group has informal representation upon a host of other organizations. Its members play multiple leadership roles.

However, critics charge that, in some cases, this has led to more emphasis on concerns of upper level persons than the rank and file of the poor handicapped. Many informants suggested that this group "had the ear of government" well beyond what might have been expected from its size. Others spoke of very substantial power struggles within this group for leadership positions and policy formulations.

Turning to organizations representing specific disabilities, the **Spinal Injury Association (SIA),** with its 1,800 handicapped members and additional affiliate members, constitutes an aggressive force in the handicapped movement. Their informant and their literature spoke of a wide variety of service offerings, including a "link scheme" to bring the newly disabled into contact with the older disabled, provision of information, publication of their newsletter, as well as pressure group activities. Several informants spoke proudly of paralyzed patients chaining themselves to beds when their hospital wards were threatened with closures. Apparently, the tactic was very successful. Some informants suggested that the SIA was less radical than the Union of the Physically Impaired, of which little else was heard.

While nondisabled associate members are accepted in SIA, the ruling management committee is limited to elected disabled members. Financing is from contribution drives, but all office maintenance costs are paid from a government grant. One informant distinguished between this organization's "moderate" views and his own radical beliefs which came from his Marxist philosophy. Many informants spoke of this group's influence upon government agencies in matters concerning spinal injury, and government leaders acknowledged their respect.

Much previous research has demonstrated that typically the blind are the earliest and best organized. This was certainly true in the UK, although the heavily government-supported RNIB appeared to have "subverted" true blind influence in the opinion of some leaders. There are a considerable number of small organizations of the blind ranging from guide dog users and recreational interests to various occupations. But, two disabled organizations, the National Federation of the Blind and the National League of the Blind and Disabled dominate the scene for true representation, according to some.

The **National Federation of the Blind (NFB)** is national in scope with local chapters and about 1,000 members. One spokesman emphasized their role in representation in many coordinating groups and the struggle with associations of physical disabilities. Apparently some important benefits are denied to the blind because of definitions adopted under pressure from physically handicapped groups. NFB is exclusively a pressure group and does not provide any services. Their spokesman admitted that the National League of the Blind and Disabled (NLB), because of its resources, was much more powerful, although NLB was criticized for taking nondisabled members.

NFB seeks to address many remaining problems faced uniquely by the blind and admits that their influence has decreased as other disability groups gain power. Like RNID, the NFB fights the pressures to move away from specialized services and specialized workers that are urged for economy.

The **National League for the Blind and Disabled (NLB)** grew in sheltered workshops of the blind at the turn of the century and is a duly constituted trade union affiliated with the Trade Union Council. Nonblind workers in these workshops are accepted for membership, and union dues are paid to support the organization. All informants admit that this permits a budget about 10 times

that of the NFB, not to mention special financing during times of need from other unions. Their leader has advanced into the higher ranks of the trade union movement and indicates that the political action funds have aided many blind members of his union into local political positions. Thus, it was emphasized that the group seeks goals within society well beyond its more narrow work interests. An indication of the early history of the organization and problems faced by all blind can be observed in the following quotation from their Golden Jubilee Souvenir Brochure (Smith, 1949).

> From the outset, the League was convinced that the claims of the blind for an honourable and secure place in the community could not be attained by charitable means, but only by direct provision by the State, and the circumstance that the history of blind welfare since the beginning of the century is a record of more and more public intervention provides ample justification for this view. But fifty years ago this proposition was denounced by the charitable organisations with a fervour too often intemperate and alien to the decencies of public debate.
>
> So much so, indeed, that one is compelled to the view that, as the League's spokesmen alleged, these outbursts were often evidence of the fear that public control would be to the detriment of established vested interests. The fact, too, that the League was continually producing evidence to support its contention that, in many charitable agencies, only a small proportion of the money subscribed by the public found its way into the pockets of the blind, while a substantial percentage went to pay inflated official salaries or was wasted due to the incompetent way their affairs were conducted, was hardly calculated to make it popular in such quarters.
>
> In its first published programme in the columns of the "Blind Advocate," the objects of the League were stated as being:

(1) To promote brotherly love and unity among the blind of the United Kingdom.

(2) To procure State aid in place of the present voluntary system.

(3) To secure the application of the Factory Acts in all public institutions for the blind.

(4) To remove all obstacles to the employment of the blind.

(5) In all possible ways to improve the moral, social, and political condition of the blind throughout the country.

These aims were to be continually proclaimed as the years went on, until some of them have become basic principles in public policy. Others still remain to be attained, and the Organisation, therefore, has still its tasks to perform.

The League did more, however, than show blind men and women the way towards the solution of their material problems.

Its programme also had a spiritual side. It taught those whom it enrolled the gospel of comradeship, and enriched their lives thereby. By encouraging them to take an active and intelligent interest in trade unionism and politics, by making them aware of the social background of their time, it made them good citizens and conscious members of the working class. It is in no small measure due to the influence of the League that, today, blind people in increasing numbers, are to be found participating in the work of Local Authorities and other public bodies, thereby vindicating its contention that blindness does not condemn a man or woman to play a negative role in society, but leaves them capable of making a positive contribution to the corporate life of their fellow citizens. (pp. 11-12)

NLB informants indicated that strong measures were essential in gaining objectives over the years and emphasized how this would have been impossible were it not for the financial and other supports stemming from their trade union position. For example, resources to pay for bussing marchers had been essential as well as the strike support funds and office support involved in organizational activities.

One informant discussed details of social disobedience actions in the past and some contemplated in the future. For example, when a march upon Parliament would not be allowed to terminate in view of the building, officials were threatened with a termination of the march by a large group of blind in an important intersection of major streets, which would have clogged London evening traffic for hours. Another ploy was to tie up all elevators in a government building for hours with blind passengers by regularly holding doors open or pushing all floor buttons. NLB compared negotiations with government and RNIB to other union bargaining measures, and long-range strategies were developed. The philosophy appeared to be to employ increasingly stronger tactics when weaker measures were ineffective. An indication of NLB thinking can be obtained from the following quotation from another part of the previously cited literature (Smith, 1949).

> Throughout the years 1917, 1918 and 1919, the League's demand for an Act of Parliament became more and more insistent, until continued official indifference impelled the organisation to launch a campaign calculated to gain for its case the greatest attention from the authorities and the general public alike. Protests were voiced from the gallery of the House of Commons: and League demonstrators were dispersed by the police when, in defiance of the law, they attempted to hold a meeting in Trafalgar Square when Parliament was in session. These and similar incidents served their purpose by effectively arousing public interest. ...
>
> It was agreed, therefore, to arouse public support by organizing a march of League members from various parts

> of the provinces to London. The marchers, two hundred and fifty all told, left their asssembly points at Newport (Mon.), Manchester, and Leeds, on Easter Monday, 1920; passing through all the chief provincial towns on their way to the Capital. Everywhere they were warmly received, and the meetings held in each centre they visited were attended by great crowds of enthusiastic sympathisers. In addition, the march received notice in every local and national newspaper on a scale which the most sanguine could not have anticipated. In short, sympathy and interest was aroused to a degree which has been seldom paralleled. (pp. 14-15)

One NLB informant expressed the personal philosophy that severe disability meant limited opportunity unless accommodations and equalizing supports are provided by society, a move that society will resist through lack of understanding, apathy, and economic self-interest. Thus, it is essential for the disabled to use every available tactic to seek understanding, produce involvement, and, if necessary, inconvenience society and produce guilt until compliance is achieved. It was admitted there is a fine line to walk in producing guilt without fostering devaluations and in inconveniencing society without raising counterproductive hostility.

Government officials referred to this organization with some awe and respect, while acknowledging that the leadership is "honorable" and that they will carry out agreements.

Finally, there are a number of disabled organizations oriented to specific functions. The **Disabled Driver Association** grew from crucial mobility needs of the handicapped and appears to have started with users of the government-provided three-wheel, enclosed "invalid cars." Many leaders were involved in this group in earlier years, and it appeared to spearhead the drive to gain the current mobility allowance that allows a regular cash payment to disabled individuals with severe mobility problems. The allowance can be used as payments toward automobile purchase under specific conditions.

This association was contrasted with the **Disabled Drivers Motor Club,**

which was characterized as more social, prone to bigger car usage, and oriented also to providing certain services and equipment for car usage. Many informants stressed the impact of this group in influencing government regarding the critical mobility problems of the disabled. Other examples would be the **Circle of Guide Dog Users** and **POSSUM Users Association.**

Cleavages

Sociologists routinely speak of cleavage problems in discussing minority power movements, and this is no less true of the disabled. Several regularly experienced issues can be identified from those sprinkled through the previous pages. In mixed groups, the disabled faction frequently polarized from the able-bodied segment, and a struggle for power and policy direction emerged. The disabled charged that the other faction could not really grasp their problems, while the able-bodied defended a right to leadership from recorded achievement and alleged better ability. The newly disabled often split with the older disabled and this difference took many forms ranging from selection of tactics to objectives. The older were typically more restrained, moderate, and prone to less drastic measures. Groups of the sensory disabled frequently broke with the physically-impaired on many issues, often based on eligibility criteria for desired benefits and the belief that too broad an inclusion might threaten securing the provision. Sometimes the difference was simply over what objective should receive higher priority in joint actions.

Less evident, but noteworthy, were differences between those with handicaps that involve brain or central nervous system function and all others. One informant stated that it was sad but true that persons with brain impairment seldom achieved general leadership status because of the disability's impairment to this role. Several referred to the split between the higher educated and brighter with the average disabled group.

Cleavages often manifested themselves in struggles over representation, and a common problem experienced is whether, in a coordinating group, representation on the governing board should be according to the membership size of the organizations or if each organization should have one vote. Obviously, if representation is by size, the disabilities that are most common would dominate and priorities would emphasize their needs.

Such predictable cleavages clearly undermine the effectiveness of handicapped power, and many leaders spoke earnestly of searches for a solution.

Tactics

Any observer is impressed by the strong differences in belief expressed on the subject of tactics, yet there appeared to be some patterns. Organizations of the handicapped clearly were willing to engage in stronger measures than those for the disabled. Many observations supported the charge that voluntary groups have too many ties to government, are too dependent upon contributions from a favorable public, and have too many role conflicts to utilize powerful measures. Allegations that radical measures are counterproductive simply could not be substantiated, although investigation for such examples was constantly pursued. The common trend was to attempt education, petition, persuasion, and debate before engaging in demonstrations, strikes, or acts of social disobedience. However, the urgency of the issue, the length of frustration, and the militancy of the group influenced this decision.

Combining information from all informants, it appeared that some issues were resolved by conservative measures, but many others required moderate tactics, and yet others could not have been resolved short of the forceful actions that were utilized.

Beyond the tactic, many suggestions regarding techniques emerged. One very successful leader advised the following: Don't take more than 20 minutes of a politician's time. Seek out those who appear sympathetic and abandon others. Refrain from social disobedience that drastically harms the public. Be certain that positions taken are accurately and articulately submitted. Give credit publicly to involved politicians. Be prepared to provide much time in drafting position papers and announcements as the price of most politicians' support. Finally, at all costs, within the organization, prevent individuals who cannot provide a good image from representing the cause, no matter how well-intentioned and deserving they are.

Other Problems

Referring back to the three possible types of adjustment to oppression, acceptance as manifested by apathy appeared a prime problem. Several leaders

disclosed that it was necessary to begin with an emphasis on socializing in order to produce enough attendance so that more fundamental issues could be addressed. Some groups engaged in recruiting drives for solutions, others did not. One research project found that disabled persons joined many groups totally unrelated to disablement. Some beginning projects to enhance awareness and heighten consciousness were noted, and they used techniques strikingly similar to those employed in the feminist movement in the US.

Lack of resources was a problem greatly diminished by government support of associations. Informants all desired greater support levels but indicated that prior to this assistance, their organizations had floundered and spent most of their time in merely surviving.

The personalities of leaders and personality conflicts among leaders was a more substantial problem. Clearly, leaders often had to direct their groups away from ill-advised goals and reinforce needed initiatives. There appeared to be a complex relationship between the circumstances of an organization and the caliber of the leader, in that even poor leaders achieved some success in favorable circumstances while excellent leaders sometimes were held back by unfortunate events. Several disabled leaders expressed difficulty in promoting realistic goals and the timing of activities to meet them. Particularly, compromises necessary in coordinating groups were often hard to explain to the member groups that might see only the loss of their priority.

One informant complained that the dominant position of the voluntary organizations resulted in the stealing of the better disabled leaders away from their groups. It was interesting that many disabled leaders in voluntary groups expressed personal positions at some variance from their group's official stance. These personal views were usually stronger.

Despite these problems, accomplishments by the handicapped community are very substantial, especially during the past decade, and the reader is referred to other books and reports regarding social policies and benefits for the disabled (Carnes, 1979; Frieden, Frieden and Laurie, 1981). There was complete agreement that most of these provisions that enhance opportunity and foster equality would not have been forthcoming were it not for the efforts of the voluntary and disabled associations. Further, an integral element in this achievement was the degree of representation achieved, an accomplishment that in turn prompted the dynamics by which favorable policies were obtained.

RESULTS: SWEDEN

The author's assumption that Sweden represented a far point on the continuum of progressiveness with reference to the handicapped clearly was supported by all experiences and observations. Findings so closely corresponded to statements made in source documents that reliance on extractions provides a better report than personal constructions on many topics. The Swedish handicapped movement appears evolved far beyond a domination by voluntary associations, and handicapped citizens own their power in its most fundamental meaning.

It was not necessary or even desirable to pursue investigation through a proliferation of diverse organizations because of their effective coordination, integration, and national-level representation. Interviews were conducted with leaders of every significant national organization and coordinating group, and considerable time was directed to government officials to confirm the reported state of affairs.

An explanation of the handicapped movement in Sweden is provided by the following quotation from Gardestrom (1978).

> The main aim of the handicap movement is to influence society to create a better situation for the handicapped, and in this work it has adopted this tradition of dialogue and co-operation between popular movement and society. The handicapped movement has been at work in a favourable climate. The economic and political development of the last few decades has resulted in Swedish society being able to be generous towards underprivileged groups. Efforts for solidarity and equality in Swedish politics have also benefited the handicapped. Social reforms, which have supported the handicapped, have been significant. The handicap movement has undoubtedly played an important role as a pressure group as well as by being able to ensure a proper drawing up of the reforms on the basis of the experiences of handicapped

persons. Parts of the handicap movement have always concentrated on working to influence society's decision-making bodies to improve the situation of their group. This method has recently come more and more clearly to the fore.

These tendencies are found in the definition of an organization for the handicapped given by the Swedish National Council for the Handicapped, which states, for example, that:

> An organization for the handicapped should work for social changes, which aim to create a better situation for the group of handicapped persons the organization represents. This means that the organization's main activity is devoted to working for social reforms with respect to, for example, the economy, labour market, social planning, communications, housing planning, education, culture, medical care, rehabilitation and leisure activities.
>
> (pp. 5-6)

The Central Committee of National Associations of the Handicapped

The Central Committee of National Associations of the Handicapped **(HCK)** constitutes the pinnacle of achievement for coordination in the handicapped movement. All informants agreed regarding its impressive influence upon government and its central role in leading the handicapped movement. By involving 23 handicapped organizations (see appendix) in a common effort, HCK provides a single voice for almost all the disabled of Sweden. As will be noted in the next section, there is one notable exception, but every type of disability is represented and achievements accomplished by the organized disabled equally affect the lives of the nonaffiliated. The following quote from HCK literature ("The New Popular Movement," 1980) provides an orientation to the organization.

The first organizations of the Handicapped in Sweden were founded in the end of the 19th century. Very early these organizations realised that they had many interests in common, regardless of the individual dysfunctions of their members. Therefore there has been a close and rewarding cooperation between the organizations of the Handicapped through the years.

In 1942 the major National Associations of the Handicapped at that time formed the Central Committee. The first task of the new committee was to respond to a governmental program concerning Vocational Rehabilitation. Ever since labour market matters have been in the centre of the joint efforts of the organizations of the Handicapped.

In 1964 the Central Committee was reorganized, and the member-organizations formed a standing committee, the HCK, and employed staff to work solely with common matters.

Today the HCK has 20 National Associations as members with a total of 230,000 individual members. Committees have also been established on the county-level and in many local communities. Members of these local committees are the chapters and branches of the National Associations.

At all levels the HCK is runned by a Board of Directors. Each member-organization has one representative on the Board. Most committees have a secretariate with employed staff.

The organizations of the Handicapped are often called the "new popular movement of Sweden." As other popular movements the Handicap-movement promotes the interest of its membership. The ideology of the Handicap-movement is based on equality, solidarity and the concept of handicap as a relation between individual and

society. The aim of the Handicap-movement is "A Society for all."

The Handicap-movement is independent of the Government, the political parties, religious and other movements. This does not mean that the Handicap-movement is not a political movement. On the contrary! As we regard handicap a relation, we believe we can change things to the better. To work for a change is a political task. The members of the Handicap-movement are all members of the electorate (about 5% of the electorate) and can not as a group be neglected by any political party.

Besides all kinds of official and inofficial contacts with parlamentarians and governments at all levels, the recent years have shown that also the Handicap movement can use rallies, demonstrations etc. to get publicity and support for demands for equality. All of the National Associations issue different papers, magazines and publications, and alone as well as within the HCK take part in reference-groups to local and national authorities. (pp. 1-2)

Discussions with HCK leaders indicate that constant efforts are required to maintain smooth functioning of the group, and many problems discussed in the previous section about the UK are experienced. The need to "uplift the thinking" of members was stressed along with continual compromise. The problem of representation was solved by allowing one seat on the national committee for each major affiliate group, except that several small organ system disability groups combined to have one representative. The organization is financed almost exclusively by government grants. One government official explained that funding groups of the handicapped was a wise social policy, because it produced mature associations with which the government can deal. Many of the organizations represented by HCK provide client services, but HCK itself is primarily a pressure and coordinating group, although this effort requires many educational and information gathering functions.

HCK has formal representation in most structures affecting the handicapped but is willing to sponsor demonstrations and engage in other forceful tactics if necessary. Critics charge that it is not responsive to grass roots membership, since policies are derived by discussions at the top among national representatives. Supporters respond that this is the only manner in which a diversity of groups with differing priorities can successfully work together. It is interesting to note that many organ system disabilities not typically organized in the US are represented in HCK, but some of these feel that their priorities too often get shoved aside by the needs of larger associations. All informants agree that the fantastic social policies and benefits for the disabled in Sweden would not have been possible without the pressure that came from several powerful handicapped vehicles, foremost among which was HCK.

Several patterns were mentioned by informants, and they suggested that these patterns occurred in other countries as well. According to this view, disability groups start with sensory loss conditions, such as the deaf and the blind, then spread to physical disabilities. They tend to start in schools or facilities where many disabled are together and face common unmet needs. (In Sweden, supplies, libraries, and the like were demanded first). The movement towards organization then spreads to those who become disabled later in life, bridged in part by a continuity from graduates of institutions where organization had already taken place. Disabled groups face growth and interpersonal problems similar to the group processes of other kinds of organizations, and resolutions easily stem from the same methods brought to bear upon similar problems in these other groups.

The Swedish tradition of group cooperation aided the development of handicapped groups by providing a fertile soil. The split with the National Association for the Handicapped (DHR), discussed in the next section, troubled HCK leaders who stressed that discussions toward reunion were underway. Several views regarding this tragic split were provided by different informants, but several factors, at least, appeared responsible.

"Charity groups" admitted to HCK offended DHR. And the change in DHR's name implying representation of all the disabled troubled HCK, which believed that DHR primarily reflects viewpoints of the physically disabled. Voting representation was then, and now, an issue, since there are several other

associations representing the physically disabled in HCK. Personality conflicts between the past leaders of HCK and DHR also appeared responsible. Philosophical differences appeared involved in that the national system of DHR was very responsive to local desires in goals and priorities, while HCK structure demanded compromises that were not practical to take back for local validation before action. While it was not emphasized, many signs of struggle between HCK and DHR were evident behind the scenes for representation on national committees and handicapped councils.

The impression was gained that government was pressuring both groups to reconcile their differences and offering financial rewards if this were accomplished. Both groups expressed the need to unite but recognized that as major competing national programs, there would have to be substantial compromise on both parts.

In operation, HCK forms panels, taking care to maintain the same representative balance as the group as a whole. The panels consider issues and recommend actions, priorities, or topics to be pursued. Member organizations are not prohibited from individual approaches to legislative processes either nationally or locally. Informants viewed the national effort as very successful but admitted that local efforts varied considerably, depending in part upon the strength of personalities involved.

Handicapped leaders in Sweden were well-informed on an international basis. This is unlike the US disabled who know little of international activities, or leaders in the UK who, in the author's opinion, incorrectly believe the US far ahead in handicapped groups. The UK leaders were, however, somewhat more accurate in their knowledge of the situation in Sweden.

National Association for the Handicapped

The National Association for the Handicapped (DHR) has 47,000 members, local groups in 24 counties, and competes with HCK as a national association. As was mentioned, at one time it was part of HCK but withdrew. Informants implied that it mainly represents the locomotor impaired, and a spokesman cited several disability groups DHR represented that were consistent with this concept. Interest was expressed in a reunion with HCK but in a smaller, five-member organization, with greater consolidation of the smaller individual associations around disability categories.

The organization started in schools for the severely disabled in western Sweden along with another group that had developed among severely disabled adults. Ultimately both joined to form DHR. Problems with financing threatened early survival and drives for contributions, sales, and lotteries occupied much time. Early efforts were in providing services, then political activities developed and grew to become organized legislative programs. Spokespersons emphasized membership by politicians and that their president was an important member of Parliament.

Early needs in the area of mobility stimulated the organization, and its first achievements were in the area of reduced car taxes. Then came financial assistance in obtaining cars, and this evolved into activities regarding housing, general welfare, access, and other areas. Along with HCK, DHR has formal representation in many instrumentalities of government including welfare, schools, transportation, and employment. The national committee has 12 elected members from the counties, but the association's director selects representatives for governmental representations.

Services include cash grants to help purchase appliances, recreation homes, education, and information provision. The importance of tangible goals was stressed and how the ability to provide services enhances membership and power. In statements similar to other groups, the crucial importance of salaried staff workers was underlined. Early fund drives were used to generate finances for this purpose. According to one informant, without salaried staff, the objectives of an organization must be highly constricted, and little can be done beyond socializing. It was admitted that, beyond salaried staff, most work is done by a very few people.

The goals of DHR, while multiple in their specifics, are in general to improve the attitude of society toward the disabled and to produce social change for assistance to the handicapped.

One outside informant stated that <u>for</u> organizations were usually "on the political right," but that DHR, while a <u>for</u> association and not strictly "of the handicapped," was an exception. Several observers commented that in the competition for representation between HCK and DHR, HCK would ultimately win if DHR did not compromise more to achieve a reunion. Of probable significance is the fact that HCK has changed top leadership in the last decade

while DHR has not, and many of the old ideas continue among DHR leadership. Beyond this, the classic collision between the sensory disabled and the physically disabled appears to be symbolized in this struggle.

Handicapped Councils

Almost every informant pointed to the handicapped council system as one of the most noteworthy achievements of the handicapped movement. Apparently in Sweden, prestigious commissions are appointed to study social problems, and their recommendations usually become law. Thus, the handicapped council system was recommended by this type of commission and quickly put into place, even though legislation was never passed. A grasp of the scope and significance of this system may be gained by the following extract from Gardestrom (1978).

> In order to increase the opportunities for contact between the authorities and the organizations for the handicapped special co-ordinating bodies, councils for the handicapped, have been set up at the different levels for political decisions i.e. local authority, county council and central government. The councils for the handicapped include representatives of the authorities immediately responsible for handicap issues and representatives of the organizations for the handicapped. The chairman is in most cases a politician involved in decision-making on this issue.
>
> The councils for the handicapped at the municipal and county council level have recently been the subject of an evaluation from which it appears that the councils function primarily as bodies for discussion and information. The handicap movement has expressed the wish that the councils should be given more decision-making functions, but there would then be a risk, as many politicians have pointed out, of the councils gaining a position outside the conventional politically elected bodies, which would not be desirable. (p. 7)

A day spent with one local handicapped council was almost overwhelming because of the extent and depth of communication between these disability representatives and government officials. The group, which was acknowledged to be one of the more successful organizations, included five categories of representation: blindness, deafness, physical disability, medical conditions, and psychiatric illness. One spokesperson emphasized how important it was to have communication with government officials when policies were in the early stages and consequently required less pressure to make changes. The group met regularly with counterpart local officials concerned with areas of importance to the disabled and, beyond this, members regularly conferred informally with many officials and politicians.

A theme heard frequently during interviews in Sweden was stressed here, "It is important for the disabled to show themselves." By this they meant physical representation at meetings, participation in community affairs, appearance on the streets, and so forth. Demonstrations were not favored unless other tactics had failed, but it was admitted that often this had been resorted to.

Recruiting members and maintaining attendance in their sponsoring disabled groups was admitted to be a problem. National leaders in the handicapped council system strongly emphasize the need for political involvement on the part of the disabled and the belief that social justice ultimately will triumph. These informants contend that for groups are not really pressure groups, and, without experiencing the disabling condition, cannot maintain the needed assertiveness. Another noteworthy comment was that conflicts over policies of integration often appeared in which the blind and deaf resisted concepts of total integration while the physically impaired and certain other groups fought for increases.

Employment appeared to be the most constantly distressing problem despite the very progressive policies of the Swedish Labor Market Board. It was also acknowledged that, while most groups pushed for broad social objectives, newer medical disability groups often focused upon narrow goals such as government support for vacation trips to warmer climates for their health. It was also readily admitted that groups varied widely in the realism of their objectives.

It was admitted that some local handicapped councils fared better than others and that frequently this was attributable to the quality of disabled

representation. Good representation meant assertive, bright, and dedicated persons. All granted that it took work to produce understanding in government officials regarding the problems of the disabled and their right to full participation. The theme of "rights" was encountered again and again and contrasted with charity, the crucial difference being that provision of services should be on the basis of the right to full equality and not because compassion prompts assistance for humanitarian purposes. Charity can be withdrawn: rights remain.

Swedish Federation of the Visually Handicapped

The Swedish Federation of the Visually Handicapped (SRF) constitutes the other remaining large handicapped group in Sweden. This organization is described as follows ("The New Popular Movement," 1980):

> The Federation of the Visually Handicapped is the oldest organization of the Handicapped in our country. It was founded in 1889. The present membership is 7,350. The actual number of registered visually impaired (blind and partially sighted) in Sweden is approx. 24,000. The SRF is organized with regional and local federations. (p. 3)

SRF acts as an agent of the government for a host of services but takes pride that it is an of organization that limits membership to blind people. Among the services it maintains are a national system of "social counselors" (which may be better interpreted as "blind adjustment counselors"), blind adjustment centers, publications in Braille, and funding for research and demonstration projects.

In many ways, it resembles the RNIB, but it appears freer from direct government control even though it operates heavily from government grants. One informant stated that a previous head of SRF had developed important political power by initiating and maintaining a secretarial service for members of Parliament. Certainly, it is no accident that the head of SRF moved to also head HCK upon the death of Dr. Richard Sterner. SRF was characterized as one of the more radical groups in HCK by several informants who also conceded that

SRF was very successful. At the time of this research, SRF was insisting that public newspapers and magazines should provide free Braille or taped editions as part of their social responsibility. SRF leaders had traveled internationally to a considerable extent and discussed problems facing the disabled with a broad perspective.

Adult Education

Sweden's system of adult education appeared to play a very significant role in the handicapped movement. In a form that is considerably different from the US, Sweden has a comprehensive system of almost free-standing educational structures for adults. These are government financed, even though they often are closely associated with other social institutions such as labor unions. Study circles are common and can take forms barely resembling education in a narrow sense.

Handicapped leaders utilized resources of the adult education program to offer group educational activities that included the following emphases: rights and benefits, medical aspects of disability, group processes, disability awareness groups, and concepts of political activism. Research involved outreach efforts to determine disabled interests in group meetings, amount and type of group association, and so forth. Salaried staff, media production capacity, duplication, and many other types of services available through the adult education programs greatly aided handicapped groups. Several informants volunteered that the adult education system had been used extensively to prepare materials used in disabled groups and to stimulate interest in attendance.

Problems and Tactics

While sufficient problem areas remained that were similar enough to establish that we were dealing with the same phenomenon, there appeared to be a significant shift in the pattern by virtue of Sweden's advanced position. Difficulties remained in apathy, recruiting, and meeting attendance but appeared less than in the UK and far less than in the US. Finances were cited as problems by a few informants, but this was almost infinitesimal compared to the UK, a fortunate situation clearly created by government funding.

However, there was a dramatic increase in problems of cleavage, disabled

group conflicts, and leadership/personality disputes. This last was not so much within groups but between associations. In general, the groups appeared to be far more mature than in the UK. It should be emphasized that this maturity is a matter of degree, for all problems found in one country existed in the other. The nature of cleavages also was shifted from primary conflicts between young/old, able-bodied/disabled, and so forth to serious difficulties between the sensory-impaired versus the severely physically handicapped and the medically disabled. Possibly these cleavages are not really more pronounced but just highly visible in the otherwise cooperative and highly organized activities of the handicapped movement.

Tactics also appeared different in emphasis while not in kind. That is, both the UK and Sweden utilized the same tactics, but in Sweden the disabled appeared more willing to use drastic measures, in general, yet had less occasion to do so. Again, this is a relative matter judged against the substantially higher activity level in Sweden. It is tempting to interpret that freedom from "for" groups makes this possible. More importantly though, it is apparent that multiple and effective channels of communication, advice, and influence are available to the handicapped, which may decrease need for drastic measures except in "sticky" issues.

Several informants stated, "It is popular to listen to the disabled in Sweden." Equally, many informants stated that the handicapped movement had developed and taken strength from previous popular movements such as temperance, religious reform, and the trade union movement. The implication was that society had been prepared by these reform movements to better accept the handicapped movement and provide support. One informant philosophized, "Your country must fully accept the trade union movement before it can the disabled."

DISCUSSION: IMPLICATIONS FOR THE UNITED STATES

If one finding were considered the most important, it would be the crucial support of handicapped groups by government. Until funds were provided for maintenance functions and salaried staff, handicapped groups hardly survived. Yet with funds for office operations, publications, salaried staff, and travel, groups rapidly increased in activity and influence. This finding was so dramatic

that the case can be made that organizations of the disabled should relinquish all other goals and direct their energies into securing a stable support base. The example of Europe predicts that the achievement of other objectives will ultimately follow.

The assumption that processes of struggle for equality and opportunity among the handicapped would parallel that seen in racial minority groups appears well-justified by the findings. The statements of black leaders asserting that whites cannot understand their situation sound much like disabled leaders' claims that, "You must have experienced the disabling condition..." The movement away from segregated facilities, the demise of the attitude that denial of equal treatment is really for one's own good, stiff resistance to full participation, which is costly, are but a few examples of the striking parallels. In the author's opinion, the US appears 50 to 60 years behind Sweden in this evolution of the handicapped movement and possibly 30 years behind the UK.

There is a concept that states that small additional increments in freedom from oppression lead to disproportionately large increases in strivings for equality. From this, one would predict a rapid escalation in the magnitude and intensity of tactics used by the disabled in the US in the next two decades. The US disabled so far have engaged little in strikes, social disobedience, and disruptive actions, and inevitably they are coming. Also, the movement of funds for services from government agencies to groups of the disabled is also predictable. This trend could be minimized if agencies involved consumers and became more responsive to felt need, but this research suggests it is not likely. There is a type of potential tragedy in this, because trained professionals truly are needed by the disabled to properly utilize these resources, and too often they are left with the shrinking agency.

Assuming that the more severely disabled are the most oppressed, the schism between the severely disabled sensory loss groups, and the physically and medically disabled over the desired degree of integration suggests some interesting speculations. If those more oppressed exhibit less striving for freedom, perhaps the sensory loss groups' resistance to integration represents fixation at the withdrawal level of reaction, while the physically disabled, less oppressed, have advanced to the aggressive level. If so, it is then predictable that the striving of the physically disabled will begin to decrease while the sensory loss

groups will rapidly increase striving until they reach the top of the curve. A final prediction might be that at a certain point in the removal of oppression, cleavages would gradually diminish in the handicapped community. Considering the relative position of Sweden and its remaining cleavages, the US will experience great intensification of cleavages in the handicapped comunity during the foreseeable decades.

There are devices that might somewhat assist development in the handicapped movement and minimize some types of problems. Sweden's use of adult education poses fascinating possibilities for innovation in the U.S. Also, some techniques already existing in the U.S. should be applied to the disabled. For instance, interpersonal training systems, widely used in industry and some health care systems, would appear highly useful for groups of the disabled and their top coordinating committees. These techniques have proven to be very effective in reducing group and personal conflicts. Systems of leadership development, also used widely by industry in the US, could also help the handicapped movement. It would seem advisable to direct some interests and resources into these very fundamental capacities even at the expense of immediate, tangible benefits.

Understanding that a receptive attitudinal and philosophical climate is necessary before progression in human rights is usually achieved, more emphasis on the constraining forces in life and society would appear to be useful in educational efforts. Many citizens of the US truly do not understand that freedom of opportunity is denied to the disabled by environmental and psychological barriers. Education toward this enlightenment and the understanding that society owes handicapped persons the removal of such obstacles as a right not as a charity-inspired gift would appear to merit considerably more emphasis. In the writer's opinion, too many public relations announcements stress vague, general statements to the effect that a disabled person can make contributions if given a chance. The result is that everyone is for the truism without understanding where the obstacles are and the necessary cost to society for their removal. However, "awareness days" are now beginning to address this, and news coverage allows the public to clearly view constraints.

Most disabled in the US have little concept of the differing ideas in Europe or the fantastic measures (by US standards) gained to secure more equal opportunity. Greatly increased education in this is needed to help motivate

group formation, attendance, and willingness to compromise. Minority groups predictably experience higher aspiration levels as gains are made and viewed in others. Early reports on this present research were received by some disabled groups with skepticism, then astonishment and the angry question, "Why can't we have that here?" They found it hard to believe that, based on the belief that all citizens are entitled to an equal share in public resources, the severely handicapped of Stockholm, Sweden who cannot use the excellent subway system are entitled to an alternative use of taxies and pay only the equivalent subway fare. The disabled of the US need more information on the developments in Europe and assistance with the growth process that lies before them.

One argument frequently encountered regarding the social policies and benefits found in Sweden is that they are prohibitively expensive. It is true that the average Swede pays about a 45% income tax, and many informants were questioned about this. "We accept it," they said, "because we feel that we get our money's worth." They pointed to their many support systems and contrasted them with alleged US public support of politically favored industry, right-wing dictatorships, tax loopholes for the wealthy, etc. and indicated that it was understandable that US citizens were cynical about taxes. Their conclusion was that the US society could and would support these programs if there were not so much resentment against use of tax dollars in general.

The resistance of "for" organizations to abandoning control is another predictable problem, yet one which must be overcome. It appears clear that they are necessary in early stages of evolution but, like the parent, they must be prepared to let go as their "children" reach maturity. Predictably, some will be overprotective parents and, for the best of motives, will try to continue protection. Young groups, like children, must make some mistakes to learn and grow. As was stated, "the handicapped must show themselves," and this is never more important than in their own structures. It would be hoped that the inevitablity of this process would persuade resistant "for" leaders to stop opposing the tide and, like a good parent, assist the disabled toward maturity and independence.

In a thought-provoking article on the subject, "Strategies to Make Bureaucrats Responsive," Delbert A. Taebel agrees that the problem is substantial (Taebel, 1971).

> Yet, there is growing awareness that these efforts have been largely fruitless, that the political system remains unresponsive. The governmental bureaucracy has been among the most unresponsive components. (p. 38)

Taebel writes that solutions using minority group pressure often do not account for the stresses faced by bureaucrats. These stresses are identified as inadequate resources, physical/psychological threats, and role conflicts. Officials often cope with the stress of limited resources by developing stereotypes that rationalize away categories of clients by asserting that they really cannot be helped anyway. The physical/psychological stress drives the bureaucrat to keep control of clients and situations. Taebel quotes Kotler (Taebel, 1971):

> As Kotler notes:
>
> > There is nothing more terrifying to a bureaucrat than the prospect of losing control over the lives of his clients. To lose these small opportunities means the loss of the personal power that our paternalistic system gives bureaucrats as a fringe benefit and calls a moral obligation. Having no political liberty themselves, administrators cannot understand the claim of local liberty--let alone appreciate it. (p. 40)

The two main types of proposed solutions, organized client group pressures and decentralization of the bureaucracy, Taebel views as proceeding from unproven assumptions. He also considers these solutions "dysfunctional" because of their effect upon the bureaucrat's stress. Pressure threatens to overextend already limited resources, and much evidence challenges the assumption that decentralization produces more responsive local bureaucrats. Further, decentralization is notoriously more expensive. Again, according to Taebel (1971):

> The assumption underlying the first strategy is that the application of pressure should cause the bureaucrat to treat the client more favorably. Looking at the three

> stresses from this point of view, two factors indicate that the strategy has the reverse effect: it provokes less favorable treatment of the client and increases bureaucrat-client antagonism. First, much of this pressure seeks to have the bureaucrat take actions that would greatly over-extend his resources. Second, pressure threatens to undermine the bureaucrat's control of the situation. To capitulate would merely heighten his sense of fear. Also, the pressure implicitly demands an alteration or even a rejection of the bureaucrat's dominant role. In sum, the strategy of pressure politics as applied by many client groups only aggravates the stresses that undermine bureaucrat-client relationships in the first place. (p. 41)

Taebel goes on to identify two fundamental approaches that take account of the bureaucrat's stress constructively. In his words (Taebel, 1971):

> The more dependent the client is on the bureaucrat, the more unresponsive the bureaucracy will be...
>
> If this proposition regarding dependency is valid, then client strategies need to be devised that either reduce the client's dependency on the agency or increase the agency's dependency on the client... (p. 41)

This may be accomplished by several strategies, according to Taebel. First, competitive structures to satisfy client needs might be formed. Bureaucrats need clients as badly as clients need agencies, but the inferior position of the clients often obscures this fact. This strategy is so antithetical to the traditional view that repudiates duplication and deifies "efficient" monopolies in service provision, that acceptance probably is not realistic. Another strategy would be to develop positive dialogue and positive input that support the bureaucracy. Examples would include minority group pressure for higher salaries for bureaucrats and increased funding for their agencies. Taebel makes the point that bureaucrats must have some tangible positive gain for themselves as

payment for the difficulties responsiveness implies. Too often client pressures have been totally negative in this context for the officials. A third strategy is development of self-help groups that will reduce dependency upon the bureaucracy. A fringe benefit is that "cutting out the middle man" is cheaper. Finally, Taebel says, if the first three cited strategies fail, a last resort remains, i.e., do away with the bureaucracy. This he considers a long-range versus a short-range strategy. It could be accomplished by either a general boycott or by overloading the agency. The goal would be to force its replacement by a more responsive bureaucracy, but it is admitted that those clients most in need of services would have to be helped by outside resources during the process, much as strike funds are used to aid union activities.

The disabled should take care in selecting the point at which pressure is applied. More dysfunctional reactions would be predicted at lower bureaucratic levels. Positive inputs by handicapped groups to federal and state legislative structures that support agency funding and/or working rewards for rehabilitation professionals are implied to be the most constructive. Sweden, in the handicapped counsels and coordination committees, appears to manifest both strategy two and three, reinforcing each other. Certainly the provision of services by groups of the disabled lessens dependency on bureaucratic structures.

The UK appears less advanced with respect to these strategies and, although not as much as the US, continues the negative pressures warned against. The writer received a clear impression that there was less hostility and more respect in the adversarial relationship between bureaucracy and client organizations in Sweden than in the UK.

Even strategy one may be realized unintentionally in both countries by the provision of similar services by many groups of the disabled and by the shrinking bureaucracy. The edict that government agencies consult with handicapped groups in formulating policy, heavily implemented in Sweden, less in the UK, and barely beginning in the US, also would satisfy Taebel's alternative of making bureaucracy more dependent upon the client group. This strategy most definitely needs continued and increased emphasis in the US but, in the author's opinion, better handicapped organizations are required to generate the representatives.

Taebel's model is striking in that it may disclose another aspect of the evolutionary process: a shift from "negative" pressure to various forms of positive strategy may accompany progress in handicapped movements.

CONCLUSIONS

1. Organizations involving disabled persons tend to evolve, beginning with control by able-bodied individuals in voluntary groups for the disabled and concluding in groups of the disabled under their own control.
2. Groups of the disabled tend to start with the sensory disabled, i.e., the blind and deaf, and move on to the physically disabled and the medically handicapped.
3. Groups of the disabled tend to start in structures such as schools, where disabled persons, often children, are put together and share common problems. Graduates continue their group associations and often are joined by adult common interest groups into a combined disablement association.
4. Early aspirations of disabled groups tend to focus on urgent practical problems such as mobility, access, housing, income, and employment but later move into cultural and societal participative goals.
5. Groups of the disabled also tend to move from an emphasis on social functions to a desire for service provision to political activism and securing rights by legislation.
6. Tactics utilized tend to vary depending on degree of frustration, failure of less aggressive measures, and freedom from ties or competing loyalties that inhibit a full range of strategies. Groups of the disabled tend to more assertive actions than those for the disabled.
7. The degree of and success in evolution of disabled groups depends upon availability of resources to supply group maintenance needs and employ salaried staff. Without financial assistance, groups struggle to survive and have little impact on society.
8. Certain cleavages predictably develop and the success of their resolution greatly affects the success of the handicapped movement. Important cleavages typically include able-bodied versus disabled, sensory disabilities versus physical/medical conditions, newly disabled versus older, and brighter/professional versus disadvantaged.
9. Paralleling the group evolution, the degree of handicapped representation develops from that which is extremely limited in numbers to tokenism to substantial advisory roles in major societal institutions to an end point of

autonomy in decision making. The speed of evolution can be greatly influenced by the quality of representatives selected by the disabled community.

10. The availability of democratically derived, high quality representatives from a strong disabled organizational base stimulates a reciprocal response from societal institutions, including governmental structures, that accelerates the process of participative influence.
11. Several problems typically manifest themselves including the need for strong, realistic leadership; overcoming apathy; avoiding personality conflicts and exploitation; avoiding self-defeating, short-term goals; and using power gained in a mature, responsible manner.
12. When the coordination phase is reached, conflicts regarding the manner of the power balance on the coordinating committee will involve several issues of which the most important are: determining which disabilities will have unit category representation versus heterogeneous conglomerations of several handicapping conditions, and whether member organizations will have one vote per association or a number of votes depending on membership size.
13. The entire phenomenon of handicapped group evolution will manifest great similarities to the processes noted in racial group formations and their struggle for equal rights and opportunity.
14. As opportunities and rights are gained by the disabled, the aspiration level will increase disproportionately with increased pressures for more and faster attainment of opportunity. This will produce consternation in the forces of reaction that allowed gains in the belief that they would terminate pressures.
15. The US position on an evolutionary continuum predicts that pressures for increased quality and opportunity from the handicapped community will accelerate greatly in the next decade and result in tactics of far greater aggression.
16. Unless rehabilitation agencies engage in far greater efforts to involve the handicapped community, service provision and related funds will gravitate into organizations of the handicapped to the detriment of these agencies.
17. A crucial process in this evolution will be the degree of societal support for

handicapped groups. If extensive financial assistance is furnished, the groups will develop into mature, responsible institutions before the inevitable process places power into the hands of unprepared forces to the injury of the disabled and society.

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APPENDIX

Organizations of and for Disabled People in SWEDEN

Appendix

From: "The New Popular Movement: The 20 Members of the Central Committee of National Associations of the Handicapped." (pp. 3-9)

Swedish Federation of the Visually Handicapped

Synskadades Riksförbund (SRF)
Office: S-122 88 Enskede

The Federation of the Visually Handicapped is the oldest organization of the handicapped in Sweden. It was founded in 1889. The present membership is 7,350. The actual number of registered visually impaired (blind and partially sighted) in Sweden is approximately 24,000. The SRF is organized with regional and local federations.

The National Association for Parents of Deaf Children

Riksförbundet döva och hörselskadade barns målsmän (DBM)

Office: Box 3080, S-700 03 Örebro

The National Association for Parents of Deaf Children was founded in 1949 and is the coordinating body for the local parents' associations at the schools for deaf and hard of hearing pupils. Its membership is at present 2,400 distributed between six local branches.

The National Federation of Hemophiliacs

Föreningen för blödarsjuka i Sverige (FBIS)

Office: Box 23089, S-104 35 Stockholm 23

The National Federation of Hemophiliacs was founded in 1964. It has at present about 600 members in seven local branches.

The National Association of the Deaf-Blind

Föreningen Sveriges dövblinda (FSDB)

Office: Sandsborgsvägen 52, S-122 88 Enskede

The National Association of the Deaf-Blind was founded in 1959 and it has at present 120 members. The total number of deaf-blind persons in Sweden is estimated at 400. A deaf-blind person is a person who cannot get information either by reading or by listening.

National Association for Mentally Retarded Children, Youth and Adults

Riksförbundet för utvecklingsstörda barn, ungdomar och vuxna (FUB)

Office: Box 5410, S-114 84 Stockholm

The National Association for the Mentally Retarded was founded in 1956. The FUB has approximately 6,000 members in the 117 local branches of the organization. The total number of mentally retarded is usually estimated to be one per cent of the population, i.e. around 80,000 people in Sweden.

The National Association of the Hard of Hearing

Hörselfrämjandets Riksförbund (HFR)

Office: Box 5615, S-114 86 Stockholm

The National Association of the Hard of Hearing was founded in 1921. Today the HFR has a total of 35,000 members in 160 county and local branches. According to public investigations, there are 650,000 hard of hearing persons in Sweden.

The National Association of Ostomy Patients

Svenskt Förbund för ileo-, colo- och urostomiopererade (ILCO)

Office: Box 2004, S-291 02 Kristianstad 2

The National Association of Ostomy Patients was founded in 1965. It has approximately 3,200 members in three county chapters and local groups.

The National Multiple Sclerosis Society Association of the Neurologically Handicapped

MS-förbundet, Riksorganisation för neurologiskt sjuka och handicappade (MS)

Office: David Bagares gata 3, S-111 38 Stockholm

The MS Society was founded in 1957 and has at present 50 local branches with a total of more than 10,000 members. The estimated number of MS patients in Sweden is 10,000-15,000. There are around 60,000 Swedes who are neurologically handicapped.

The Swedish Psoriasis Association

Svenska Psoriasisförbundet (Pso)

Office: Sveavägen 31, S-111 34 Stockholm

The Swedish Psoriasis Association was founded in 1963. At present it has 24 county chapters and 54 local branches. There are about 200,000 persons suffering from psoriasis in Sweden, and 16,000 of them are members of the Pso.

The Swedish Association for Motor Handicapped Children and Young People

Riksförbundet for rörelsehindrade barn och ungdomar (RBU)

Office: David Bagares gata 3, S-111 38 Stockholm

The Swedish Association for Motor Handicapped Children and Young People was founded in 1955. It has at present 11,000 members in 28 local branches.

The National Association for Cystic Fibrosis

Riksföreningen för Cystisk Fibros (RfCF)

Office: Barnmed. Kliniken, Akademiska Sjukhuset, S-750 14 Uppsala 14

The National Association for Cystic Fibrosis was founded in 1969. At present it has approximately 500 families as members. The RfCF estimates that one out of 3,000 newborn babies has CF.

The National Association of the Heart and Lung Diseased

Riksförbundet för Hjärt- och Lungsjuka (RHL)

Office: David Bagares gata 3, S-111 38 Stockholm

The National Association of the Heart and Lung Diseased was founded in 1939. The association has nearly 17,000 members in 120 local branches. The number of heart and lung diseased in Sweden is estimated at 500,000-600,000.

The National Association of Laryngectomees

Riksförbundet för laryngektomerade (RLE)

Office: Box 6135, 102 33 Stockholm 6

The National Association of Laryngectomees was founded in 1965 and has at

present seven local branches in the country. The membership is approximately 800.

The National Association Against Allergy

Riksförbundet mot allergi (RmA)

Office: Box 45153, S-104 30 Stockholm

The National Association Against Allergy was founded in 1956 and has at present about 15,000 members in 130 local chapters and branches. Approximately 12-15% of the Swedish population are estimated to suffer from allergy to the extent that they have to consult a physician.

The National Association Against Rheumatism

Riksförbundet mot reumatism (RmR)

Office: Box 6707, S-113 85 Stockholm

The National Association Against Rheumatism was founded in 1945. It has more than 40,000 members in 94 local branches. Rheumatism is the largest physical disease in the country, with some 250,000 Swedes experiencing it.

The National Association of Persons with Kidney Diseases

Riksförbundet for njursjuka (RNj)

Office: Huvudskärsvägen 36, S-121 54 Johanneshov

The National Association of Persons with Kidney Diseases was founded in 1969. It has at present approximately 2,000 members in seven local branches.

The National Association for Social and Mental Health

Riksförbundet for social och mental halsa (RSMH)

Office: Box 523, S-101 27 Stockholm

The National Association for Social and Mental Health was founded in 1967. It has at present about 7,000 members in its 16 local branches. 116,000 individuals in Sweden are treated in mental hospitals, and the RSMH estimates that approximately half a million inhabitants are severely handicapped due to psychological circumstances.

The National Epilepsy Association (The Swedish Branch of International League Against Epilepsy)

Riksförbundet för svensk epileptikervard (RSvE)

Office: Stora Sköndals sjukhus, S-123 85 Farsta

The National Epilepsy Association was founded in 1954. Today the association has some 1,200 members in 17 local branches. The total number of epileptics in Sweden is estimated to be one person out of 200, i.e., 40,000 persons.

The National Association for the Traffic and Polio Injured

Riksföreningen för Trafik- och Polioskadade (RTP)

Office: Box 1121, S-171 22 Solna 1

The National Association for the Traffic and Polio Injured was founded in 1946 as an organization for the polio injured. Since 1970, the organization is also open for traffic victims. The total membership is about 55,000, of which the main part are supporting members. The association has 20 county chapters and nine local branches.

The National Association of the Deaf

Sveriges Dövas Riksförbund (SDR)

Office: S-793 01 Leksand

The National Association of the Deaf was founded in 1922. It has 3,950 members in 50 local branches. Members in the SDR are persons who have been deaf since childhood. Since the total number of deaf persons in Sweden is approximately 6,000, the SDR is the association with the highest membership rate.

Since the paper "The New Popular Movement" was written, the following organizations have joined HCK.

The National Federation of Psychotic Children

Föreningen för Psykotiska Barn (FPB)

Office: Box 5410, S-114 84 Stockholm

This federation was founded in 1973 and has at present about 600 members in eight regional branches.

The National Federation of Diabetes

Svenska Diabetetsförbundet (SD)

Office: Box 226, S-101 84 Stockholm.

This federation was founded in 1943 and has at present about 28,000 members in some 80 local branches.